* **Importance of Ability to Consent for Teens**
  + Increases teen use of proper health care and preventive services
  + May be only source of care, esp. for lower income teens—In 2006, over 60% of women who received health care services at a Title X clinic identified that as their usual source of health care (NPR, April 2011)
* **Minor Consent and Confidentiality Laws**
  + Every state has some form of law that allows teens to consent to their own health care (outside of parent consent)
  + Some issues are covered by federal law and apply to all states
  + Some areas of consent rely on state law
  + We will examine first Federal Laws and then State  Law
    - Issues common among states
    - Issues specific to Ohio medical care
  + Some based on status of adolescent:
    - Emancipated minor
    - Mature minor doctrine
    - Minor in the military
    - Minor self supporting away from parents or are a parent
  + Some based on service being sought:
    - Contraceptives, STI dx/rx, substance abuse counseling
* **Mature Minor Doctrine**
  + Developed and recognized in several state courts
  + According to the mature minor doctrine, when a minor has the capacity to give informed consent for care and voluntarily gives such consent, and the care is within mainstream medical practice and is not provided in a negligent manner, a health care provider will not be liable for relying on the minor’s consent or for not obtaining the consent of a parent for the care
  + Generally over 15 in Ohio
* **Emancipated Minor**
  + Legal mechanism where by a minor is freed from parental control
  + Granted by court
  + Generally involves:
    - Married minor
    - Self supporting away from parent
    - In military
    - Some states if have own child
    - Incarcerated in some states
  + Ohio has no law allowing minor to petition court for emancipation
  + If minor is law fully married or in military in Ohio, they are emancipated (de facto)
* **Issues Delineated in Federal Law or at Federal Levels**
  + Family Planning teen consent provisions in:
    - **Title X Provisions**
      * 1970 Public Health Service Act section aimed at funding family planning/reproductive services
        + Also breast/pelvic exams
        + Does not directly fund abortion
        + At no or reduced cost
      * Requires Title X Providers to provide confidential family planning services *regardless of age*
      * Preempts state laws that require divulging services to parents – Provides access then in all states
      * Title X providers:
        + Planned Parenthood/Family Planning Clinics
        + Health Depts., Hospitals/Univ. Med. Ctrs.
        + Community Health Centers
    - **Medicaid**
      * Medicaid law demands family planning access for sexually active women and adolescents
      * Also includes confidentiality provisions
    - **HIPAA**
      * When a minor is allowed to consent for health care and does so, the minor is the “protected” person under the Privacy Rule
      * Also true if a parent agrees to a provider-­‐ adolescent contract
      * Confidentiality: What do I share with parents?
      * Defers to state law:
        + If prohibits disclosure, can’t disclose
        + If states require disclosure, must disclose
        + If state law *permits* disclosure, provider has discretion to disclose (ethics of profession and situation important)
        + If state law is silent on an issue, physician has discretion
  + *Summary of Family Planning/Reproductive Health Services*
    - Even if a state lacks an explicit law providing consent and confidentiality for contraceptive services, there are some routes to same:
    - Title X Clinic
    - Use of mature minor doctrine (unless state has rejected mature minor doctrine)
    - Teen able to consent: Military, emancipated, self supporting, parent of own child—varies by state
    - Parent has signed pre-existing consent agreement for teen and doctor
    - No known legal cases against provider for providing contraceptives without parental consent
* **Ohio Specific Issues of Consent and Confidentiality and Teens**
  + *Sexuality and Family Planning*
    - Minor can consent to diagnosis and treatment of STD—All 50 states
    - Minor may seek contraception without parental consent if deemed mature (or in Title X funded clinic)—Includes emergency contraception
    - Teen will need to find free clinic or pay for costs to keep confidential (insurance bill has details)
  + *Abortion*
    - Ohio law requires parental notification/consent at least 24 hours before
    - If parents refuse, minor may:
      * Seek judicial bypass
      * Family member over 21 may provide consent in cases of abuse or fear of harm/abuse to pt
      * Parents not notified in these cases
    - Process: Call planned parenthood or go to Juvenile Clerk of  Courts Office–often granted (86% rate in Ohio) (Life News.Com, 2003)
  + *Mental Health Services*
    - Minor 14 and greater can consent to out patient mental health services:
      * No more than 30 days total treatment
      * No more than six sessions
      * If this happens, parental consent/notification needed
    - Medication requires parental consent
  + *Drug and Alcohol Services*—Minor 12 and older can consent to drug and alcohol services
  + *Sexual Assault and DV*
    - Teen can consent to evidence collection and examination in situations of sexual assault
    - Minor in a IPV situation can obtain a restraining order form the County Court of Common Pleas  (Parent must be notified)
  + *Emergency Needs*
    - Care for any true emergency can be given without consent
    - Once emergency is over, effort should be made to obtain consent for ongoing or other care
    - No right to confidentiality
* **When Can/Should Adolescent Confidentiality Be Breached?**
  + Reminder—If a minor consents to own health care, information is to be confidential.
  + *Breaching Confidentiality*
    - Mandated by law
      * Subpoena
      * Health surveillance (STD, assault reporting)
      * CPS/Law Enforcement reports for child abuse and neglect
    - Risk of harm to self or others
  + *Preserving Minor’s Confidentiality*
    - Speak with teen about concern if insurance is being used
    - Pay Cash
    - Use Planned Parenthood/Adol. Health Center
    - Advise office staff on how to reach minor (personal cell phone)
  + Use resources, such as local adolescent medicine specialist

Ethical Issues In Peds (Lo)

**How are ethical issues in pediatrics different?**

* Children are not autonomous
  + children cannot weigh risks and benefits, compare alternatives, or appreciate long-term consequences → incapable of making informed decisions ⇒ autonomy is less important in peds
  + parents are presumed to be the appropriate decision-makers
* Physicians should be advocates for children
  + physicians are in a position to identify situations in which a child’s health and well-being are jeopardized by their parents’ decisions or actions
  + pediatricians are given special responsibilities to intervene
* Physicians should respect children’s potential to become autonomous adults
  + when kids reach maturity they might choose values different from their parents’
  + as children grow, they become capable of making informed decisions → physicians should provide children with info about their conditions and opportunities to participate n decisions about their care

**What standards should be used in making decisions for children?** \**beneficence* = primary ethical guideline

* Children’s Best Interests
  + children are persons separate from their parents, with their own interests and rights
  + usually parents decisions’ and their ongoing involvement promote child’s best interest but some may not
  + child’s best interest includes both duration and quality of life
* Children’s Preferences
  + children’s *assent* to interventions is ethically important if it is developmentally appropriate
  + it is disturbing to force interventions on a child who can understand what will be done and is actively resisting it
* Parents’ and other family members’ interests
  + what is best for an individual child can be understood only in context of what is best for the family as a whole
  + parents cannot be expected to devote all their energy and resources to one child, even though they should make some sacrifices

**Who should make medical decisions for children?**

* Presumption of Parental Decision Making
  + parents are presumed to be the appropriate decision makers for their children
  + pediatricians refer to *parental permission* rather than consent to distinguish what people may decide for themselves from what they may decide for their children
    - parents do not have absolute power to refuse care for their children
    - parental permission should be supplemented with the child’s assent when developmentally appropriate
  + If parents want to know what the physician would do if it were their child, then it is helpful for the physician to describe the process of decision making they would use, including talking with relatives, friends and religious leaders. If parents still want to know what the physician would do, then it is appropriate to offer a recommendation based on the patient’s values and goals, which may differ from the physician’s.
  + *Emergencies*
    - physician should immediately provide appropriate treatment if no parent/guardian were available and a delay in treatment would jeopardize the child’s life or health
    - delaying treatment would violate the child’s best interests
  + *Exceptions*
    - estranged parents, alcoholic or substance abusing parents, parents with developmental disability or irresponsibility lack the capacity to make informed decisions
    - court should appoint a guardian; if too slow, physicians often make informal arrangements for another relative to make decisions when parents are absent or incapable
* Adolescent Patients
  + by statute, 18 years old may give informed consent or refusal to medical care with parental involvement
  + *Mature Minors*
    - “mature minors” are ale to give informed consent and refusal
    - pt’s capacities and understanding of consequences of treatment need to be evaluated prior
    - generally 14-15 years old
    - in most states, a court must declare an adolescent a mature minor
  + *Emancipated Minors*
    - adolescents who are living apart from their parents and managing own finances, are married, have children or have served in the armed forces are termed “emancipated minors”
    - in most states, determined *de fact*o adults; some require a judicial hearing
  + *Treatment of Specified Conditions*
    - most states allow adolescents to assent to treatment for sensitive issues (STDs, contraception, pregnancy, sexual assault, substance abuse, psych issues)
    - justification: requiring parental permission would deter many adolescents from seeking treatment for important PH problems
    - however it is generally in the best interest of the minor to involve their parents
  + *Parental Requests for Treatment*
    - Supreme Court: schools may require random drug testing of athletes and students in extracurriculars
    - surreptitious testing (drug, pregnancy, etc.) in unacceptable—violates adolescent’s emerging autonomy, creates mistrust and suspicion within the family and undermines trust in the physician

**Pediatrician’s Relationship with Children and Parents**

* Disclosure of Information to Children
  + pediatricians should provide children with pertinent info regarding their care in terms they can understand
    - children who cannot understand may still want to know
    - pediatricians should also obtain the child’s assent if developmentally appropriate
  + Regarding serious diagnoses,
    - pediatricians should elicit the parents’ concerns and fears
      * parents may believe the child cannot handle bad news
      * parents may fear the child’s peers will reject them
    - physicians should explain that children usually cope better, have fewer psychosocial problems, and adhere more closely to treatment if they understand their diagnosis and therapy
* Confidentiality
  + *Exceptions to Confidentiality*
    - Physicians must report suspected cases of child abuse or neglect (overridden confidentiality, only sufficient information to warrant a fuller investigation is required)
    - Intervention might enable parents to obtain enough assistance and support to prevent further abuse; only in extreme cases are children removed from parental custody
  + *Disclosure to Schools*
    - Only information truly needed should be disclosed to schools—not a diagnosis but excused absence
    - Pediatricians might also need to arrange for children to receive medications at school
  + *Adolescents*
    - Assurance of confidentiality increases the willingness of adolescents to seek needed health care, particularly for such sensitive conditions, and to disclose info candidly to physicians
    - Many physicians provide absolute rather than conditional assurances of confidentiality but overriding confidentiality is ethically appropriate and legally mandated in several situations
      * plans to commit suicide
      * physical or sexual abuse
    - When parental disclosure is mandated, laws generally allow an exception when the physician believes that disclosure will harm the patient
    - Generally physicians should encourage adolescents to discuss medical decisions with their parents, who usually provide useful support and advice
      * Often impossible to keep information from parents
      * Doctors can offer to help adolescents disclose info to parents
      * Sometimes disclosure can be counterproductive or dangerous, such as when domestic violence is likely ⇒ best for child to confide in a trusted adult relative

**Refusal of Medical Interventions**

* *Disagreement between Parents and Pediatricians*
  + Doctors need to try to persuade parents to accept effective interventions that have few side effects
  + Physicians + social workers and nurses an mobilize emotional support and social resources to help the parents provide better care
  + If disagreement persists, next actions depend on clinical circumstances, benefits/burdens of treatment and sometimes child’s wishes
  + In rare situations, physicians should ask courts to override parental decisions (ex. life-saving therapy)
* *Refusal of Interventions of Limited Effectiveness or Great Burdens*
  + Refusal of interventions that have limited effectiveness, impose significant side effects, require chronic treatment or are controversial by informed parents should be decisive
  + Ethically appropriate even if child’s life expectancy might be shortened
* *Refusal of Effective Interventions with Few Side Effects*
  + Physicians who are unable to persuade parents to accept interventions with few side effects should seek a court order to administer the treatment
    - a court order signifies that society regards the parent’s refusal as unacceptable
    - “although parents may be free to become martyrs themselves, they are not free to make martyrs of their children”
    - court as a last resort—don’t want to disrupt parent-child bond
  + sometimes physicians defer to parents refusals because conflict between the parents and medical system would harm the child
    - ex) objections to immunizations because of religious beliefs, concerns about side effects or opposition to modern medicine
    - If the number of unimmunized children is small and herd immunity exists, then it might not seem worth alienating the parents
* *Refusal of Effective Therapy with Significant Side Effects*
  + In this case, child’s preference might be important—if an older child or adolescent makes an informed decision to undergo such treatment, then physicians should support that decision
  + If parents continue to refuse after repeated attempts at persuasion, then some physicians seek court orders to compel treatment
    - physicians need to take into account the impact on long-term parental cooperation with the child’s care
    - physicians should listen to the parents’ objections and show respect for their opinions and ongoing responsibility for the child
* *Child’s Refusal of Interventions*
  + When children refuse effective treatments, physician’s response should depend on seriousness of the clinical situation, effectiveness and side effects of treatment, the reasons for refusal, the parents’ preferences on treatment, and the burdens of insisting on treatment
  + Difficult for force adolescents to take ongoing therapies (insulin or inhalers)
  + most constructive approach is to understand the patient’s reasons for refusal, to address them, and to provide psychosocial support
  + Because it is physically difficult to force such treatments on adolescents, these refusals have been accepted particularly when the parents have supported the child’s refusal
* *HPV Vaccine*
  + objections to mandating HPV vaccinations by pro-family and anti-vaccination groups
    - mistrust of government and drug manufacturers
    - concerns about undermining traditional family values
    - concerns that the vaccine will promote sexual promiscuity
  + Public policy and clinical guidelines about the vaccine are controversial
    - involve sensitive issues such as adolescent independence, parental authority, access to health care related to sexual behaviors, and changes from traditional social values
    - unlike abortion, HPV vaccine cannot be considered morally wrong per se—its long-term goal is cancer prevention; however the vaccine must be given before sexual activity starts
  + Mandatory PH policies can be ethically justified if voluntary measures have failed, no less coercive alternatives exist, the scientific rationale is compelling, and members of the general public are unknowingly at risk
    - HPV vaccine does not meet these standards
    - HPV can be prevented by condom usage
  + Some parents delay vaccination because…
    - daughters are not sexually active
    - uncertain about long-term effectiveness
    - rare adverse effects may not have been identified
    - HPV vaccine may encourage sexual activity
  + The challenge is for doctors to help parents consider a different perspective—that their child may become more sexually active than they would like or approve
  + Some adolescents who know they are likely to become sexually active should have the opportunity to benefit from the HPV vaccination
  + most states allow adolescents to obtain care for STIs, contraception, and pregnancy care without parental consent
    - the ethical rationale is that reducing harms to adolescents and respecting their emerging independence outweigh parental interests of control over their children
    - similarly, adolescents should be permitted to receive HPV vaccination without parental permission

**Parental Request for Medications with No Medical Indications**

* parents sometimes request meds to modify their child’s behavior and enhance their school performance, sometimes so that their children are not at a disadvantage
* *Critics* object to using med to improve behavior and school performance who are not diagnosed with a condition
  + a better alternative is instruction and practice to strengthen the will of a restless and unruly child
  + unlike other parental steps to help their children, meds rupture the bond between effort and accomplishment and undermine the child’s responsibility, self-control, and sense of right and wrong
* *Supporters* rebuttal against critics
  + critics create a false dichotomy between meds and effort
    - in fact, students using stimulant meds such as coffee still must study hard to learn (coffee isn’t the kind of stimulant medication I was thinking of, Lo…)
  + critics overestimate the effectiveness of medications, which do not work for many children with problems
  + critics oversimplify by suggesting that poor school performance results primarily from a lack of will/effort
    - other causes need to be considered and addressed such as environment
* In a child with significant behavioral and learning problems who does not meet criteria for ADHD, if behavioral and counseling approaches prove ineffective, it is reasonable for informed parents to conduct a trial of medications.

**Handicapped Infants**

* 1985 “Baby Doe Regulations” set limits on decisions to withhold medical treatment from disabled infants <1 y/o
  + intended to ensure such interventions as surgery for infants with Down syndrome
  + treatment other than “appropriate nutrition, hydration, or medication” need not be provided if:
    - the infant is irreversibly comatose
    - treatment would merely prolong dying
    - treatment would not be effecting in ameliorating or correcting all life-threatening conditions
    - treatment would be futile in terms of survival
    - treatment would be virtually futile and inhumane
  + decisions to withhold medically indicated treatment may not be based on “subjective opinions” about the child’s future quality of life
  + hospital are encouraged to establish ethics committees called “infant care review committees” to advise physicians in difficult cases
* 2002 “Born-Alive Infants Protection Act” intended to reject the idea that a child’s care should vary according to “whether that child’s mother or others want him or her”
  + regulations to implement this act require physicians to make an individual medical screening examination of each child who is born alive, regardless of the estimated *in utero* weight and gestational age
* The Baby Doe Regulations have been criticized
  + primarily because they exclude parents from decision making
  + also because of rejection of the idea that maximal medical interventions must be provided unless they are futile or a child is irreversibly comatose or dying
  + critics argue that in other clinical settings, the mere possibility of survival does not require the physicians to employ all available medical technology

**Improving Access to and Utilization of Adolescent Preventive Health Care** (Results) Adolescents and parents reported that the most effective way to encourage preventive care utilization among teens was to directly address provider-level barriers related to timeliness, privacy, confidentiality, comprehensiveness, and continuity of their preventive care. They reported that incentives (e.g. cash, movie tickets, gift cards) might also be an effective way to increase preventive care utilization. To improve adolescent receipt of surveillance and guidance on sensitive health-related topics, most adolescents suggested that the best way to encourage clinician-adolescent discussion was to increase private face-to-face discussions with a clinician with whom they had a continuous and confidential relationship. Adolescents reported that the use of text messaging, email, and internet for providing information and counseling on various sensitive health-related topics would also encourage adolescent utilization of preventive health services. Parents, however, more often preferred that their teen receive these services through in-office discussions and clinician-provided brochures. State agencies, health plans, clinics, and individual providers may consider focusing their efforts to improve adolescents’ utilization of preventive services on basic structural and quality of care issues related to the clinician-patient relationship, access to services, and confidentiality.